

# Managing persistent pain in children and adolescents

Emily McGurk, Clinical Psychologist

Julia Kingsley, Senior OT

Emma Woods, Senior PT



# Learning Objectives

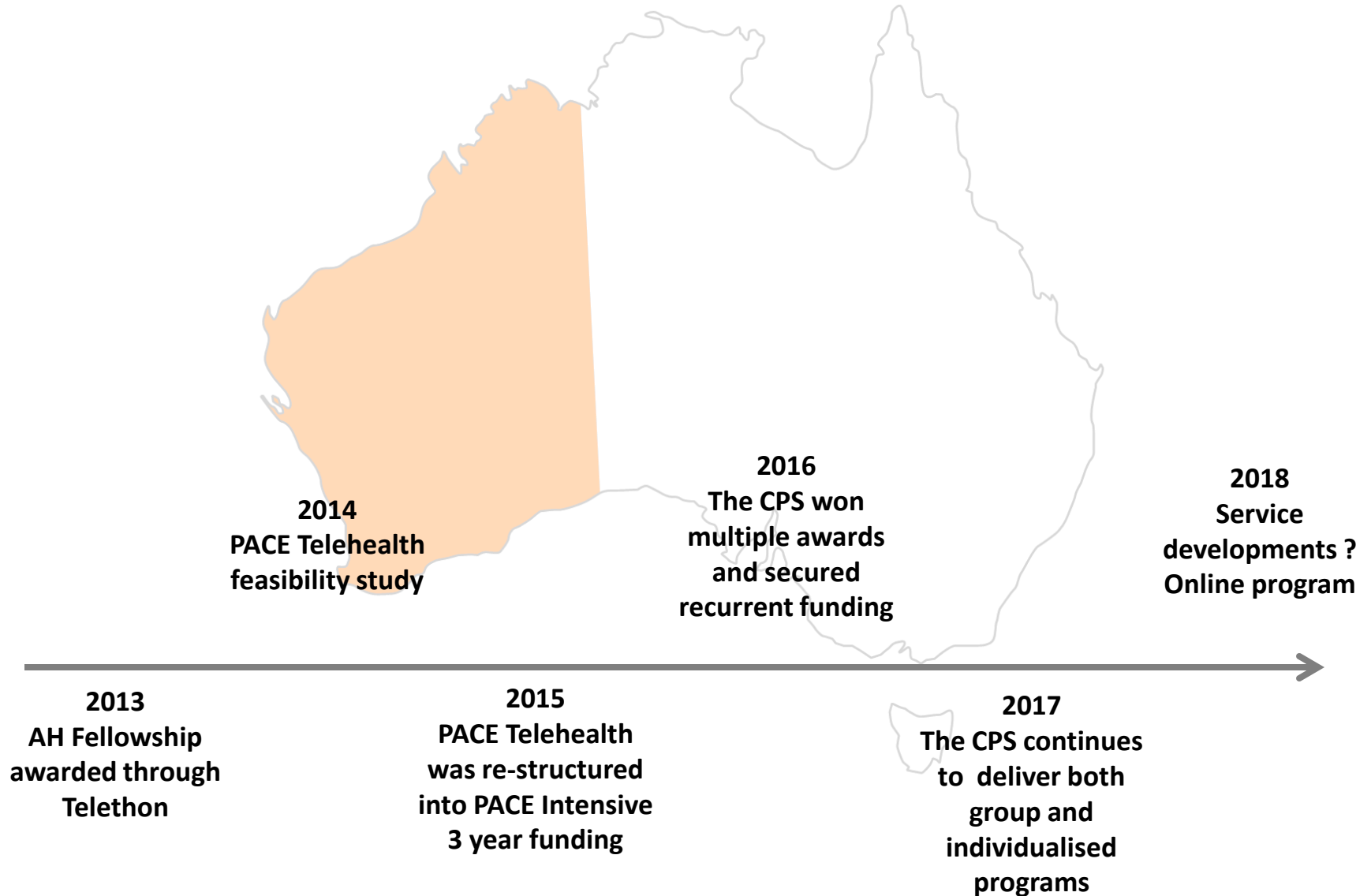
- Develop an awareness of the prevalence and impact of chronic pain on young people and their families
- Develop an understanding of the Complex Pain Service history and service development.
- Develop an understanding of the CPS service delivery model and the programs available
- Develop an understanding of the neuroscience/psycho-educational platform influencing program structure
- Develop an understanding of how to formulate and treat chronic pain
- Broaden awareness of current research undertaken at CPS related to paediatric chronic pain
- Develop an understanding of the referral pathways to CPS

# Facts and Figures

- In WA there are approximately 29,000 young people living with disabling chronic pain
- Kids with untreated Chronic Pain are more likely to have mental and physical health problems as an adult
- Significant social and financial cost
- Families are significantly impacted. The burden of caring for a child in pain is high, and their parent's mental health and productivity suffers.

(Access-Economics, 2007; Australian Demographic Statistics, 2015; Blyth et al., 2001; King et al., 2011; Walker et al., 2010)

# Timeline of service development



# The Team



Dr Kevin Murray  
Rheumatologist



Julia Kingsley  
Snr Occupational  
Therapist



Dr David  
Sommerfield  
Pain specialist &  
Anaesthetist



Dr Pavla Walsh  
Rheumatologist &  
Pain Specialist



Anna Hilyard  
Program  
Coordinator



Emma Woods  
Snr  
Physiotherapist



Leasa Ashton  
Liaison Teacher



Jessica Klye  
Administration



Emily McGurk  
Clinical  
Psychologist



Suzi Taylor  
Snr Occupational  
Therapist

... plus those team members that came before ...

# What do we do?

- We are a Cognitive Behavioural Therapy based outpatient chronic pain management service for children and adolescents, and their families.
- Our aim is to improve outcomes in areas such as psychological functioning, school participation, ADLs and physical activity
- Using neuroscience as a platform we assist children and adolescents to become independent in self management of chronic pain.
- We also support families to facilitate this process by providing parental education and ongoing support.

# Complex Pain Service Programs

## Stream 1: MEDICAL ONLY (Consultants)

## Stream 2: **PACE** INTERVENTION- Interdisciplinary (Allied Health + Liaison Teacher input + Consultants)

- Adapted for two age groups Teen (12-16 yrs) and Jnr (8-12 yrs)
- 5-6 families per group, one per school term
- 50 child contact hours over 5 weeks, 2 days per week
- 21 Parent contact hours over 6 weeks
- Individualised school case conference

## Stream 3: **INDIVIDUAL PROGRAMS / SPRING** (Allied Health + Liaison Teacher input + Consultants)

- Low disability, full school attendance
- Unsuitable for group (age, cognitive function, pathology)

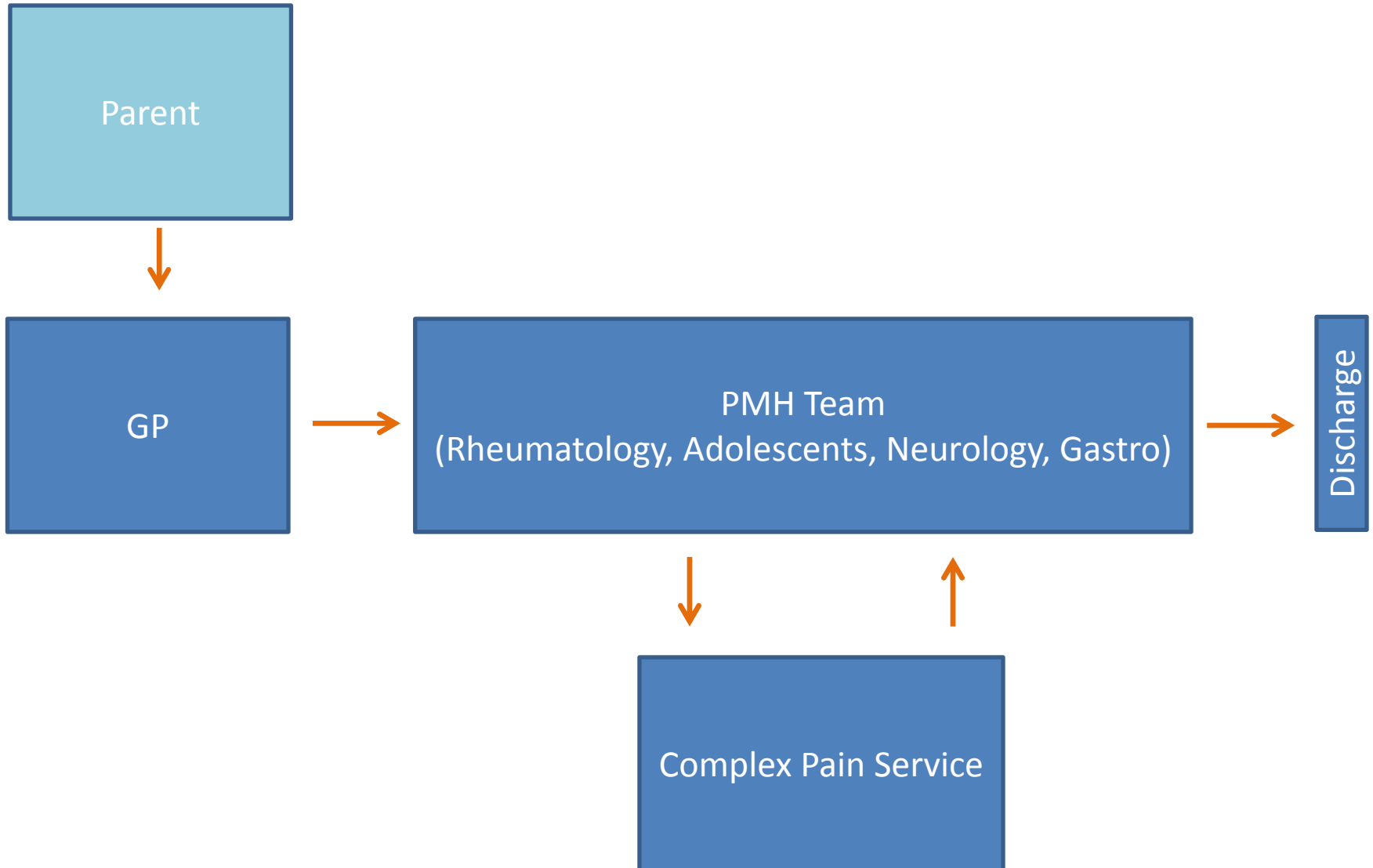
# PACE

## Inclusion criteria:

- Relevant investigations have been completed and serious pathology excluded.
- Primary carer is committed to participate in the program and accepts that no further investigations or medical interventions are required.
- Aged up to 16 at time of referral to CPS and considered at assessment to be developmentally mature enough for either a Junior or Teen PACE group program.
- Pain has been present for > 6 months, is the primary symptom and significantly affects function including activities of daily living and school attendance.
- Stable management plans in place for any comorbid conditions.
- Insufficient progression despite previously engaging with physical rehabilitation program of at least 6/52.



# Referral pathway



# TYPES OF PAIN

## ACUTE PAIN

First 6 weeks

Usually relates to tissue damage or infection

Resolves on healing

**CAN HAVE A PROTECTIVE PURPOSE**

## CHRONIC PRIMARY PAIN

12 weeks +

Initial trigger (injury, infection, stress)

Pain remains after tissue has healed

Sensitisation of the nervous system

**NO PROTECTIVE PURPOSE**

**Hurt  $\neq$  Harm**

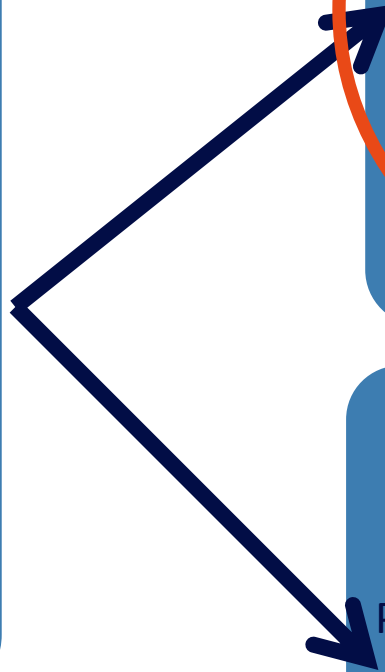
## CHRONIC SECONDARY PAIN

12 weeks +

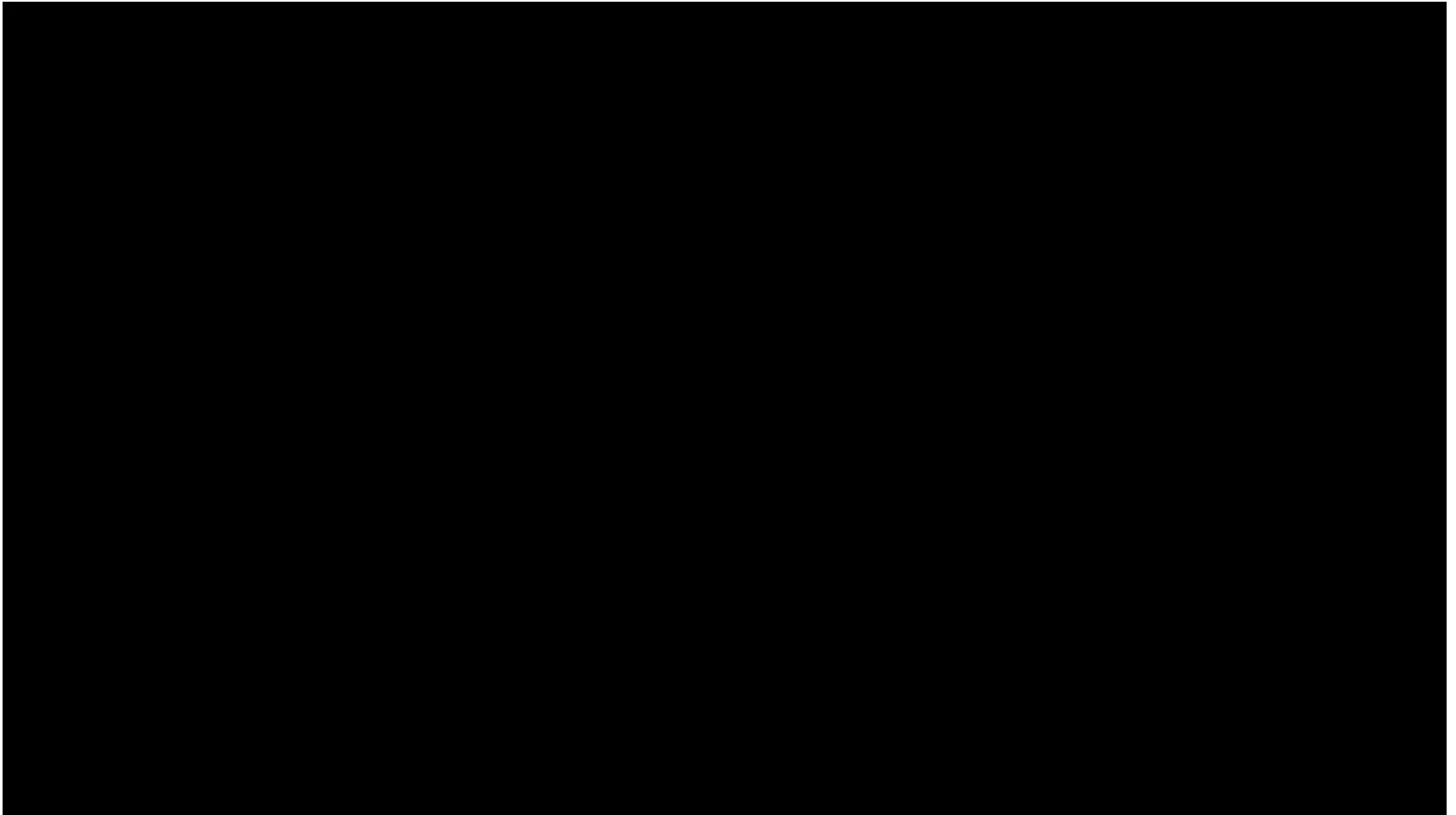
Pain as a symptom of disease process

**CAN HAVE A PURPOSE**

**...but is often disproportionate to process in tissues**



# Why pain hurts



***All pain is a **real experience...*****

***It is not psychological but  
psychological factors effect it***

# Treatment

- Pain Neuroscience
- Cognitive restructuring
- Communication
- Relaxation and mindfulness
- Goal setting
- Pacing
- Focus on emotional expression
- Exercise and movement
- Exposure to feared situations
- Sleep hygiene
- Self-soothing/ distress tolerance
- Identity work
- Perfectionism, self sacrificing work
- Setback planning
- School reintegration/school visits
- Strategies for parenting a child with chronic pain
- Healthy eating
- Manage co-morbidities
- Encouraging independence
- Risk management
- Ongoing review
- Referral – PT, individual/ family therapy

# Parents as important as the kids

1. Your child's chronic pain is due to a sensitised nervous system rather than tissue damage
2. Focus on function, rather than pain. Ignore expressions of pain.
3. Notice small changes and praise them
4. Don't reward unhelpful behaviours e.g. No screens if home sick from school
5. Engage in calm, consistent communication, stick to your plan
6. De-catastrophise your language, behaviour and challenge your own unhelpful beliefs
7. Maintain your family values/ routines
8. Encourage independent pain management
9. Be your child's parent, not their friend
10. Look after yourself!!!

# School Case Conference (SCC)

- Appropriate staff available to attend case conference including
  - Year Co-ordinator
  - School Psych
  - School Nurse
  - Pastoral care (Deputy or Head or Student Services)
- PACE team – case manager and liaison teacher
- Family – parent(s) and child
- External agencies SIDE, CAMHS

# TYPES OF PAIN

*Different types of pain – require different treatment*

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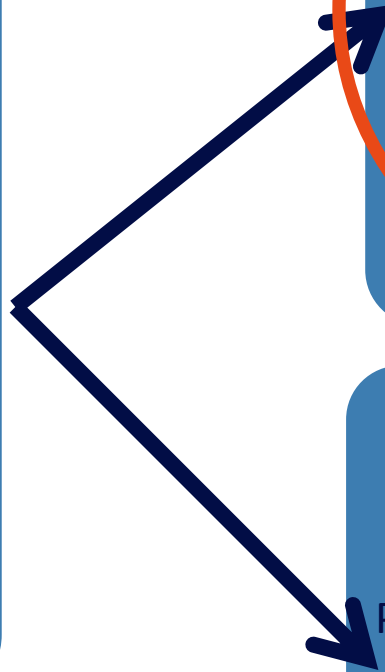
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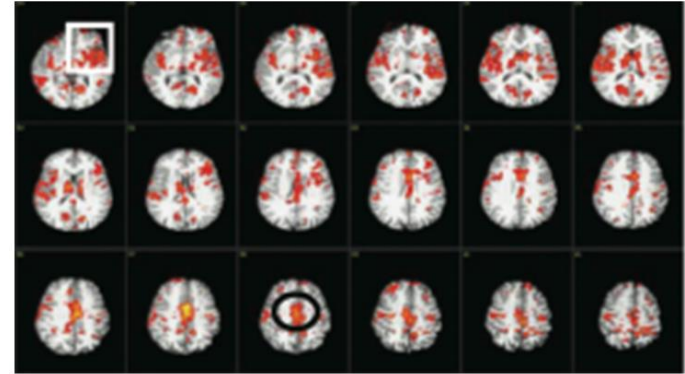




# PACE Program education

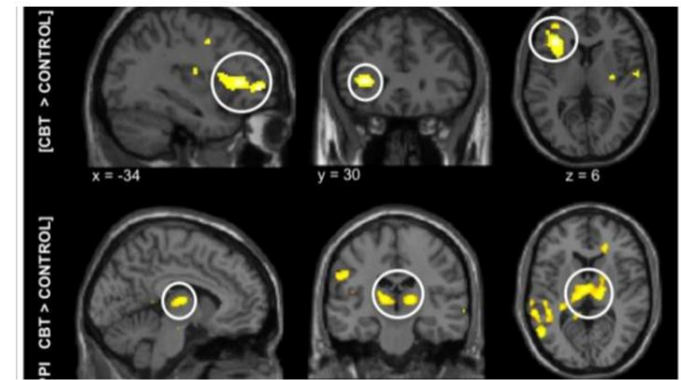
## Complex Pain Neuroscience Education

- Validation
- Pain is no longer a reliable guide



## Useful terminology/ phrases

- Hurt  $\neq$  Harm
- motion is lotion
- pace it don't race it!
- Hypersensitive nervous system = RED ALERT
- Descending inhibitory pathways = MELLOW YELLOW

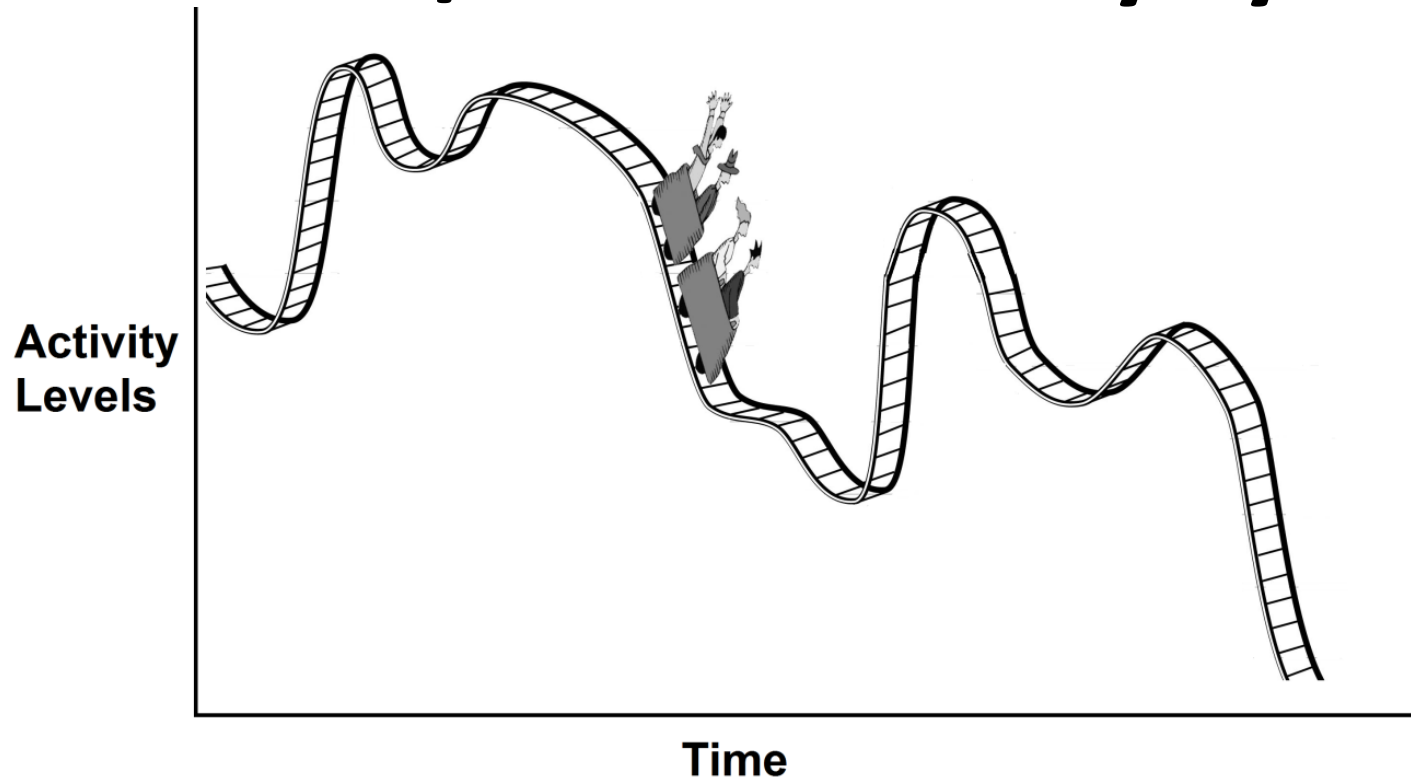


Goal: ↓ RED ALERT and ↑ MELLOW YELLOW

# **PACE Program education continued...**

- The effects of inactivity
- Decoding medical terminology
- Medication use in Chronic Pain – reduction plans
- Self management (active vs. passive)
- Return to physical activity and exercise...

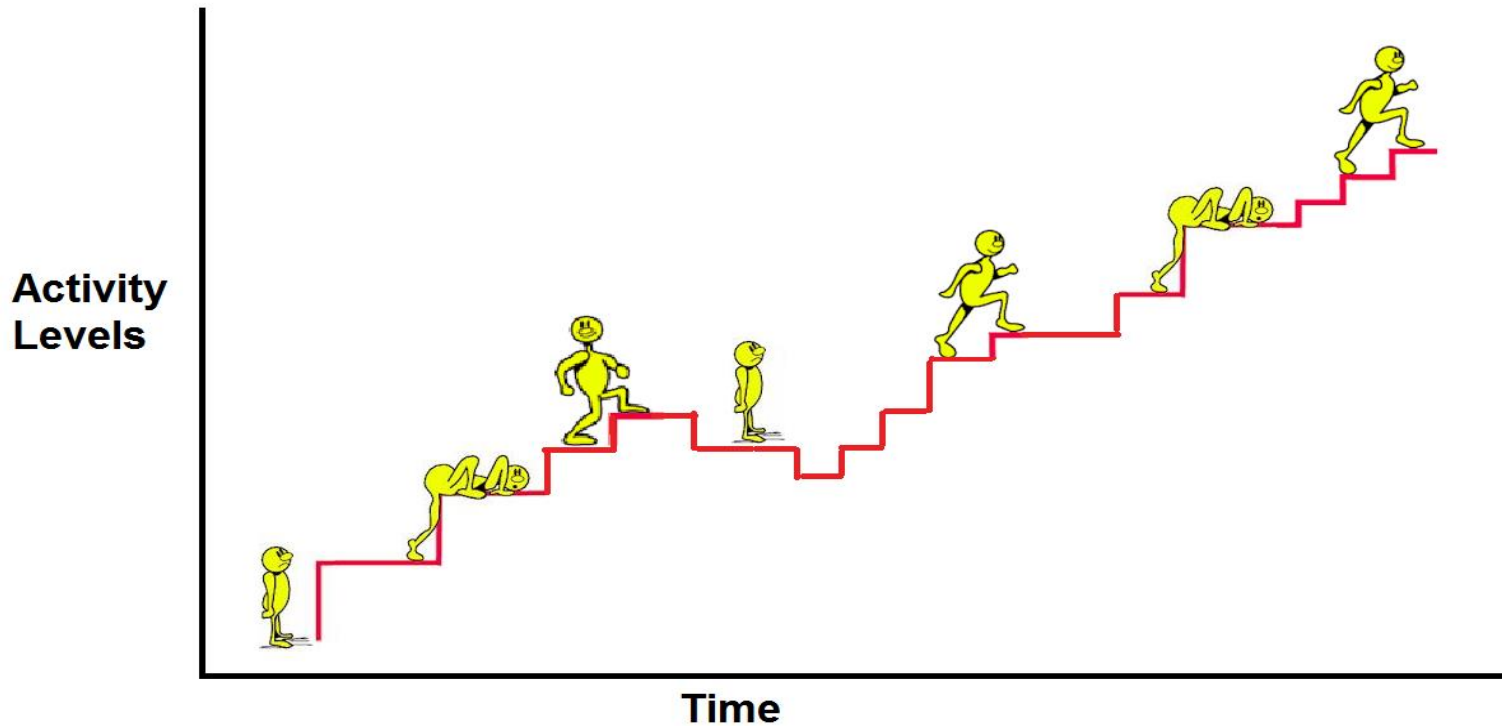
# The over/under activity cycle



- A pattern of behaviour that uses symptoms to guide activity
- Respond to pain as if it were acute (e.g. broken bone)

# How to get off the rollercoaster

## “Pace it – don’t race it”



# Avoid the Rollercoaster

## Set Baselines - Function

- Get 3 baseline measures and calculate the average (baseline)
- To calculate average
  - Add up the three measures and divide by 3
  - Eg: 8 minutes, 10 minutes and 12 minutes, so average = 10 minutes
- To calculate Baseline (that you can do on both good and bad days)

Tasks	Measurement 1	Measurement 2	Measurement 3	Average Calculation	Baseline
e.g. Sitting – school chair	5mins 28secs = 5mins	12mins 18secs = 12min	4min 52secs = 4mins	$5 + 12 + 4 = 21$ $21 \div 3 = 7\text{mins}$	7mins

# Cheat sheet

## How to calculate a baseline

Some activities are more challenging than others when you have pain. It is often hard to know how much activity you should or shouldn't do. Let's do an experiment to see how much activity your nervous system likes.

### Remember:

- Use your timer to record how long you are comfortable doing activities
- It is not a maximum or minimum and it might not be pain free
- You should be able to continue your day as normal or as usual
- You should be able to repeat the activity later

*Your baseline is safe and helpful to use, good day or bad day*

Calculating a baseline:

- Add up the three measures
- divide by 3
- confirm

= BASELINE

## How to make a progression plan

Once you are using your baseline measure for tasks and exercise, it is important to make a plan for progression. We know that the nervous system responds well to ***small, regular increases in activity when it is planned and consistent, good day or bad day.***

Some helpful guidelines:

- |  |  |
|--|--|
| <ul style="list-style-type: none"><li>• &lt;10 reps, increase by 1-2 reps every 2-3 days</li><li>• 10-20 reps, increase by 2-3 reps every 2-3 days</li><li>• 20-30 reps, increase by 3-4 reps every 2-3 days</li></ul> | <ul style="list-style-type: none"><li>• &lt;10mins, increase by 30+secs every 2-3 days</li><li>• 10-20mins, increase by 1+min every 2-3 days</li></ul> |
|--|--|

*Remember, you can pace activities down or up depending on the goal you are working towards.*

## Managing prolonged tasks (maximum durations)

- Sitting: 30mins
- Standing: 10mins
- Walking: 45-60mins
- Lying down/ resting: 15mins

# Somatic Symptom Disorder

- A. The patient has one or more somatic symptoms that are distressing or result in significant disruption of daily life.
- B. Excessive thoughts, feelings, or behaviours related to the somatic symptoms or associated health concerns as manifested by at least one of the following:
  - Disproportionate and persistent thoughts about the seriousness of one's symptoms
  - Persistently high levels of anxiety about health or symptoms
  - Excessive time and energy devoted to these symptoms or health concerns.
- C. Although any one somatic symptom may not be continuously present, the state of being symptomatic is persistent (typically more than 6 months).

Specify if - with predominant pain (previously pain disorder): this specifier is for individuals whose somatic symptoms predominantly involve pain.

Specify if- persistent: a persistent course is characterised by severe symptoms, marked impairment, and long duration (more than 6 months).

Specify current severity.

# Functional neurological symptom disorder

- A. The patient has one or more symptoms of altered voluntary motor or sensory function.
- B. Clinical findings provide evidence of incompatibility between the symptom and recognised neurological or medical conditions.
- C. The symptom or deficit is not better explained by another medical or mental disorder.
- D. The symptom or deficit causes clinically significant distress or impairment in social, occupational, or other important areas of functioning or warrants medical evaluation.

Specify type of symptom or deficit as:

With weakness or paralysis

With abnormal movement (e.g., tremor, dystonic movement, myoclonus, gait disorder)

With swallowing symptoms

With speech symptoms (e.g., dysphonia, slurred speech)

With attacks or seizures

With anaesthesia or memory loss

With special sensory symptom (e.g., visual, olfactory, or hearing disturbance)

With mixed symptoms.

Specify if:

Acute episode: symptoms present for less than 6 months

Persistent: symptoms present for 6 months or more.

Specify if:

With psychological stressor (specify stressor)

Without psychological stressor.



# Common Comorbidities

## Differential diagnoses

- Panic
- GAD
- Illness anxiety disorder
- OCD
- Depressive disorders
- FNSD
- Body dysmorphic disorder
- ED's
- Dissociative disorders
- School phobia/ refusal

# Assessment

## Family

- History of physical complaints, illness behaviours
- Responses to child's pain
- Their perception of the cause of the pain
- Family capacity to communicate about emotional issues
- Family Hx of pain/ physical health issues
- Family Hx of mental health issues
- Life events
- Trauma

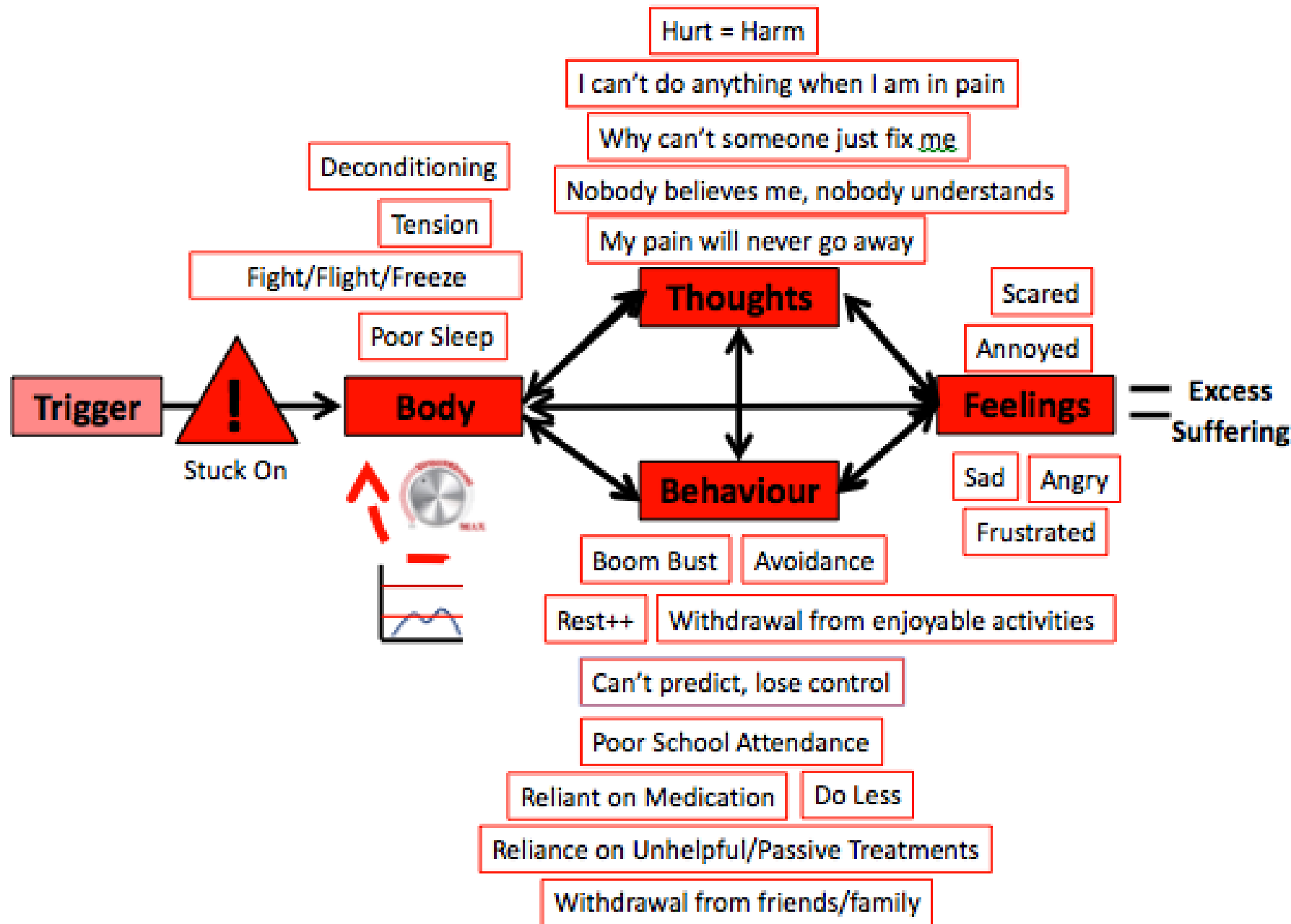
# Assessment

## Child

- History (developmental, medical, school, social, intellectual, premorbid functioning)
- Temperament
- Life stressors
- Mental health
- Function
- Physical assessment

# Assessment

- Interdisciplinary
- Engagement
- Validation
- Shared formulation



# Patient

- 17 year old girl
- 2-3 year history of abdominal pain and fatigue
- Multiple investigations
- Pain does not resolve over multiple admissions
- Mobilising using wheelchair for the past year
- Tremor developed this year
- Impact on mood, function & school attendance

# Background

- Child Dev issues: Normal
- School: Premorbid functioning – very academic, Poor school attendance post Year 10
- Social: Close group of friends
- Physical: Previously very functional, enjoyed dance

# Background/Predisposing

- Intact family, only child
- Disconnected from broader family
- Some conflict in marriage prior to pain commencing, now resolved
- Family Hx of pain
- Lots of grief and loss in the year prior to CPS referral



# Precipitating

- Hospital
  - Infections
  - Multiple tests
  - Lack of clarity/diagnosis/explanation
  - Experiences of feeling invalidated
  - Lack of re-assurance
  - Aids

# Perpetuating?

## Parental relationship and roles

- Mum puts on a brave face, distress is just below the surface, not prioritising self
- Dad wanting to help- role work/ home
- Stopped socialising/ date nights/ identity – parents of a sick child
- Reinforcing expected movement patterns

## Child

- Self sacrificing, perfectionistic, difficulty expressing needs, avoidant of conflict
- Identity
- Lack of independence, not engaging in normal developmentally appropriate activities
- Fear-avoidance behaviours
- Global deconditioning
- Boom bust activity cycle

# Protective

- All family members well engaged
- Parents very supportive
- Intelligent young woman
- Goals
- Dog
- Persistent

# Formulation

- 17 year old girl with symptoms along a conversion/somatoform continuum in context of intact but worried family
- Perpetuated by difficulty expressing her needs, perfectionistic and self-sacrificing traits, family dynamics, unhelpful thinking and avoidance.
- Iatrogenic effects

# Treatment

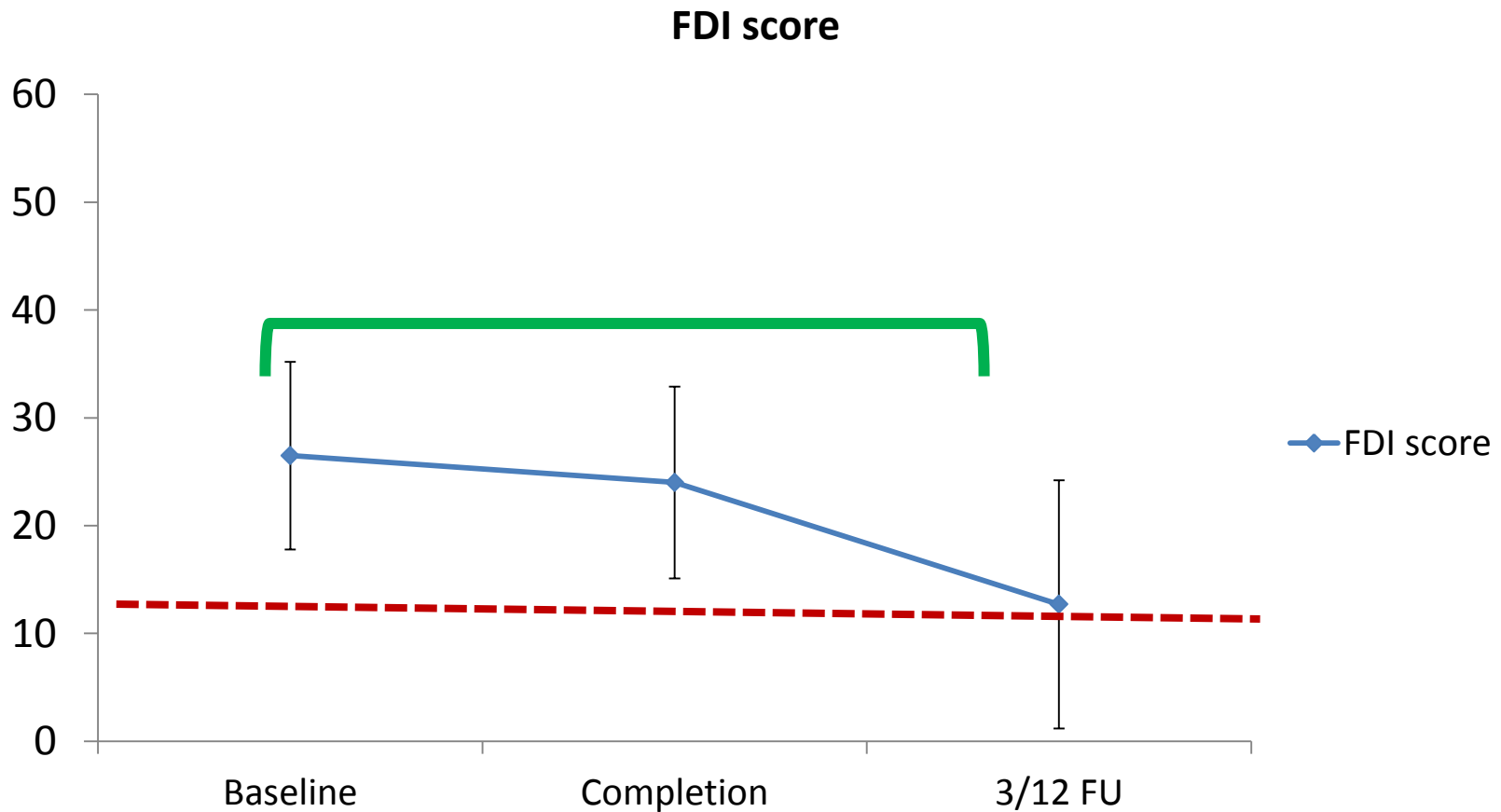
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# Outcome

- Independent standing/ walking
- Daily school attendance, completing Cert 3 in business, planning to do Cert 4
- Self care – independent
- No longer sleeping during the day
- Significantly more movement
- Thinking in more balanced ways / catching self when falling into old thought patterns
- Better capacity to tolerate distress
- Increased social engagement
- Doing more enjoyable activities and starting to identify underlying issues, pain overall more manageable
- Planning on doing floristry next year

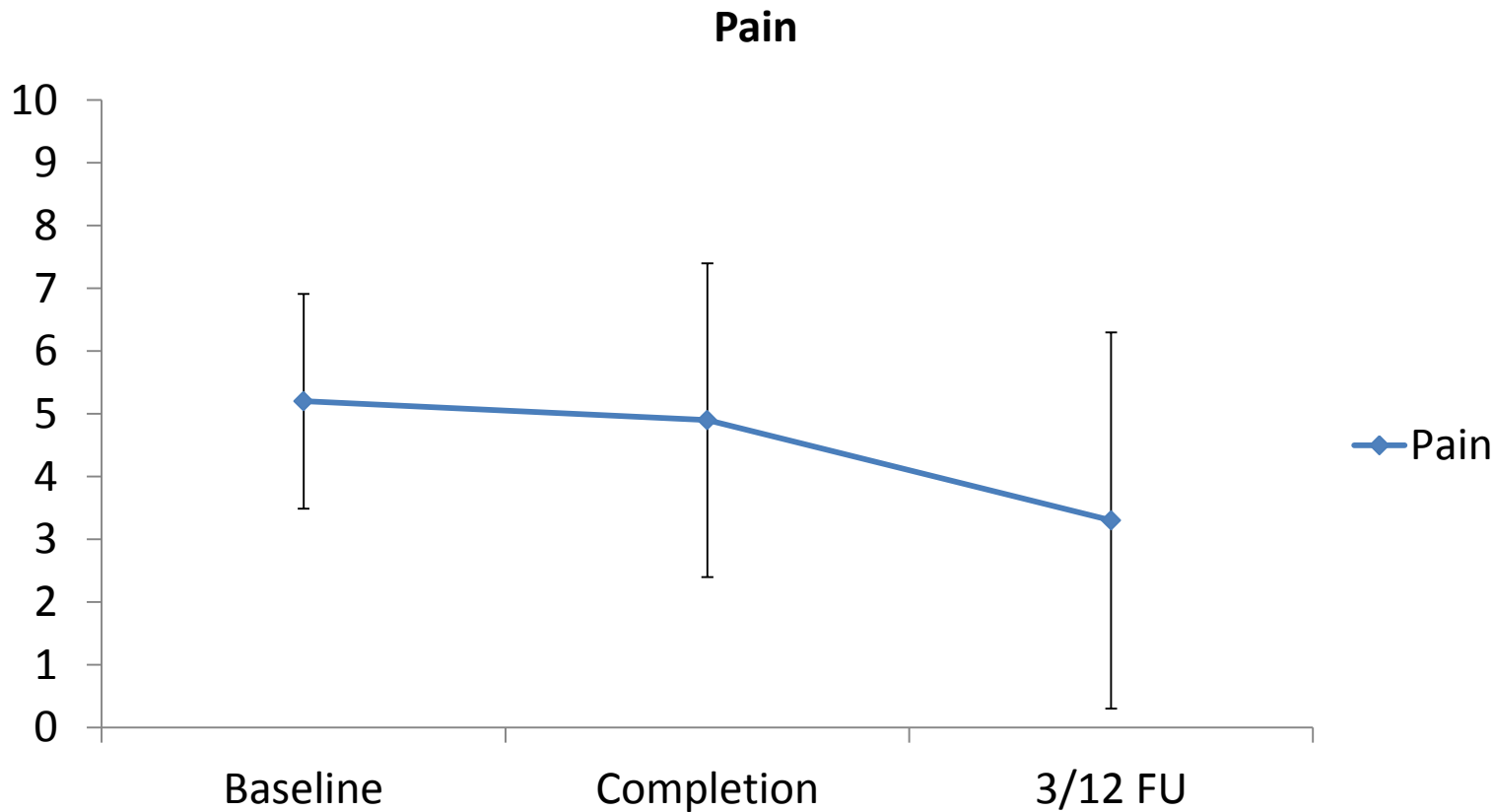
# Research at CPS

## Functional outcomes post PACE – Children and adolescents



# Research at CPS

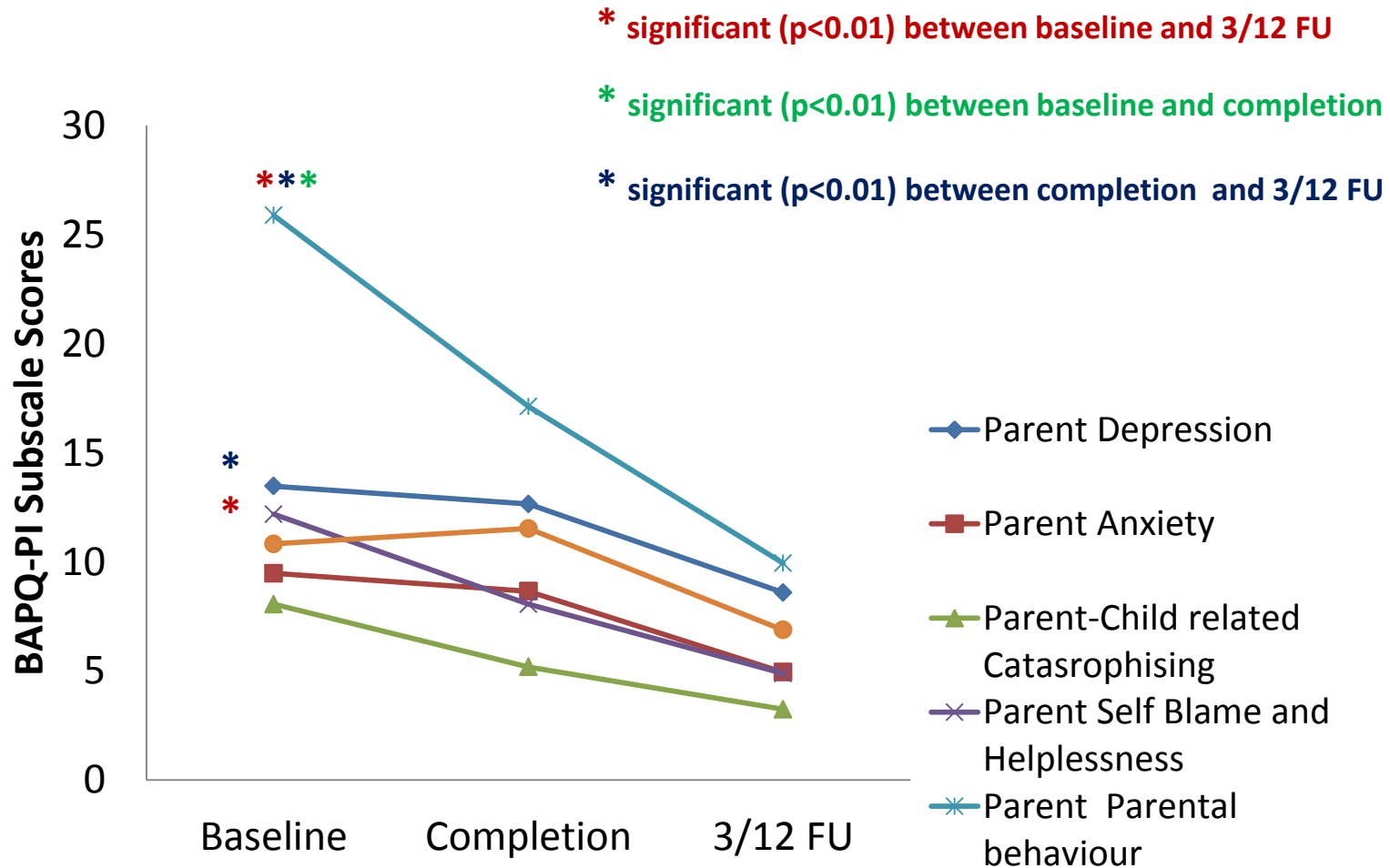
Pain ratings post PACE – Children and adolescents





# Research at CPS

## BAPQ: Parent Impact



# Outcome measures – Young People

Outcome measure	Young Person	Parent Proxy
<b>Functional Disability Index (FDI) (primary measure)</b>	✓	X
Bath Adolescent Pain Questionnaire (BAPQ)	✓	✓
Fear of Pain Questionnaire (FOPQ)	✓	✓
Revised Children's Anxiety and Depression Scale – Short Form (RCADS )	✓	✓
Brief Pain Inventory (BPI)		
Average Pain last week (0-10)	✓	✓
Six Minute Walk Test (6MWT)	✓	X
Timed up and go (TUG)	✓	X
Sit to Stand (STS)	✓	X
Emergency Department Visits	✓	X
Admissions	✓	X
School attendance	✓	X

# When to refer a young person

- When pain is getting in the way of their capacity to function (i.e. school attendance)
- Where the problem is getting worse
- When you feel it is outside the realm of your expertise

# Develop your own formulation for....



Ella is a 9 year old girl who lives at home with her mother, Stacey, father Richard, and older brother, Sam. 2 years ago Ella her appendix removed following a bout of abdominal pain. Unfortunately her pain continued. She had further tests, including MRI, CT, ultrasound, gastroscopy, colonoscopy and blood tests and all of these were normal. The doctors reassured her that everything had healed but her pain continued.

Currently Ella is continuing to attend her ballet lessons which she really enjoys. She is unable to attend school regularly and has significant problems sleeping. Ella's family had to cancel a trip to Bali they had been planning for months. Richard is frustrated and finds it difficult to understand why the doctors have stopped looking for the cause of the pain.

Ella recently confided in her aunt that she is being bullied by a girl at school.

# Or...



Jack is a 12 year old boy who lives between his mother and father houses. He is an only child and has a dog called Rufus. Jack has had severe leg pain for the past 2 years. There was nothing that Jack or his parents could identify that caused the pain to start. Jack had lots of tests, including MRI, CT, ultrasound, bone scans and blood tests, and all these were normal. The doctors reassured him that everything was OK but his pain continued. Jack has tried physiotherapy, chiropractic care, homeopathy, magnetic bracelets and lots of different medications with little long term benefit.

Currently, his pain is so severe that he spends most of his time in his room. He is unable to play football, go out with his friends, go to school or do his chores. He needs to use crutches to walk.

His mother, Heather recently has quit her job to help care for Jack and this has caused some financial stress. She is now home-schooling Jack. His father, David is frustrated and thinks Jack needs to toughen up and Heather needs to stop mollycoddling him. Both Jack & Heather believe the doctors have missed something.

Jack has started to withdraw into his room and refuses to talk to his parents. Recently, when Heather or David take him to family or social events, Jack has started to have aggressive outbursts.

# Questions?

# Resources

Retrain Pain: [www.retrainpain.org](http://www.retrainpain.org)

Pain Bytes: <http://www.aci.health.nsw.gov.au/chronic-pain/painbytes>

Pain Health website <http://painhealth.csse.uwa.edu.au/index.html>

Headache Help: <http://www.headachehelp.org.au/>

Lorimer Moseley-Why Things Hurt <https://www.youtube.com/watch?v=gwd-wLdIHjs>

Understanding Pain: What to do about it in less than five minutes?  
<https://www.youtube.com/watch?v=4b8oB757DKc>

## Relaxation Resources

Headspace: <https://www.headspace.com/>

Smiling mind: <http://smilingmind.com.au/>

## Relaxation Apps

Relax Me

Qi Gong Relaxation

# Thank you

